

# FY 2022 REPORT TO THE PRESIDENT AND CONGRESS

### Submitted by

U.S. Department of Health and Human Services (HHS)

Administration for Community Living (ACL)

National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)

On behalf of the Interagency Committee on Disability Research (ICDR)

Anjali Forber-Pratt, Ph.D., ICDR Chair and NIDILRR Director

Although ACL oversees and provides administrative support to the ICDR, the ICDR is an independent body. The views expressed herein are those of the Interagency Committee on Disability Research. They do not necessarily represent the positions or policies of the U.S. Department of Health and Human Services.

### **U.S. Department of Health and Human Services**

Xavier Becerra Secretary

### **Administration for Community Living**

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Acting Administrator

### National Institute on Disability, Independent Living, and Rehabilitation Research

Dr. Anjali Forber-Pratt Director

January 2023

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January 2024

The Honorable Joseph R. Biden, Jr. President of the United States The White House 1600 Pennsylvania Ave., NW Washington, D.C. 20500

Dear Mr. President:

The Congress established the Interagency Committee on Disability Research (ICDR) to promote coordination, cooperation, and collaboration among federal departments, agencies, and organizations conducting disability and rehabilitation research. As designated Chair of the ICDR, I am pleased to submit the enclosed *FY 2022 Report to the President and Congress*. The report details noteworthy activities of the ICDR and its member agencies during the reporting period. In these and other activities, the ICDR is committed to engaging our federal partners and stakeholders to ensure the relevance of ICDR activities to the needs of individuals with disabilities, their families, researchers, service providers, employers, and communities.

On behalf of the members of the ICDR, I appreciate your continued support of research and information-sharing that contributes to the inclusion of individuals with disabilities in the social, educational, economic, and mainstream of American society.

Respectfully yours,

Anjali Forber-Pratt, Ph.D. Chair Interagency Committee on Disability Research

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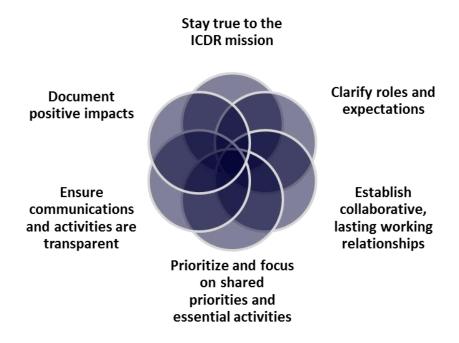
### INTRODUCTION

Authorized by the 1973 Rehabilitation Act, as amended by the Workforce Innovation and Opportunity Act (WIOA), the Interagency Committee on Disability Research's (ICDR) mission is to promote coordination and cooperation among federal departments and agencies conducting and funding disability, independent living, and rehabilitation research programs, including programs relating to assistive technology (AT) research and research that incorporates the principles of universal design (UD).

### The ICDR's charge is to

- identify, assess, and seek to coordinate all federal programs, activities, projects, and plans concerning the conduct of research (including AT research and research that incorporates the principles of UD) related to independent living;
- obtain input from policymakers, representatives from federal agencies, individuals with disabilities, organizations representing individuals with disabilities, researchers, and providers;
- share information about the research carried out by members of the committee and other federal departments and organizations;
- identify and make efforts to address areas of research that are not being adequately addressed;
- identify and establish clear research priorities;
- promote interagency collaboration and joint research activities and reduce unnecessary duplication of effort;
- optimize the productivity of ICDR members through resource-sharing and other costsharing activities; and
- develop a comprehensive government-wide strategic plan for disability, independent living, and rehabilitation research.

To meet this charge, the ICDR operates under six guiding principles:



- 1. Stay true to the ICDR mission. The committee identifies its unique niche in disability and independent living research and ensures that its efforts benefit many stakeholders and partners. Initiatives focus on the interagency nature of the ICDR and complement the work that agencies are already doing.
- Clarify roles and expectations. As the ICDR pursues its collective work, it considers and respects the diversity of partner agency missions, perspectives, priorities, and decisions by clearly communicating its expectations.
- **3. Establish collaborative, lasting working relationships.** ICDR works to build trust among committee members and partner agencies by actively soliciting diverse perspectives, positions, and opinions.
- **4. Prioritize and focus on shared priorities and essential activities.** ICDR identifies realistic and meaningful activities to develop common ground among members, capitalize on existing capabilities, and leverage resources.
- **5. Ensure communications and activities are transparent.** Communication is open and regular among committee members and across agencies. The ICDR's goals, strategies, and activities are transparent, with agency contributions openly recognized.
- **6. Document positive impacts.** Success is determined by measuring the positive impacts that disability research and collaboration have on the disability community.

### **EXECUTIVE COMMITTEE**

The ICDR develops its agenda and establishes goals and objectives through an interagency Executive Committee (EC). The EC is comprised of 17 ICDR statutory members and representation from other agencies with mission synergy and relevant interests.

In carrying out its duties, the EC

- works to promote effective interagency coordination, collaboration, and communication;
- secures the input of other federal agencies and stakeholders;
- develops and implements the ICDR strategic plan; and
- hosts meetings to advance the agenda of federal departments, offices, and partner agencies.

The following are ICDR statutory members:

- Secretary, Health and Human Services
- Director, National Institute on Disability, Independent Living, and Rehabilitation Research (Designated Chair)
- Commissioner, Rehabilitation Services Administration
- Assistant Secretary, Special Education and Rehabilitative Services
- Assistant Secretary, Disability Employment Policy
- Secretary, Defense
- Administrator, Administration for Community Living
- Secretary, Education
- Secretary, Veterans Affairs
- Director, National Institutes of Health
- Director, National Institute of Mental Health
- Administrator, National Aeronautics and Space Administration
- Secretary, Transportation
- Assistant Secretary, Indian Affairs
- Director, Indian Health Service
- Director, National Science Foundation
- Administrator, Small Business Administration

Appendix A contains a complete list of participating federal agencies in fiscal year (FY) 2022.

### **OVERVIEW OF FY 2022 ACCOMPLISHMENTS AND ACTIVITIES**

During FY 2022, the ICDR promoted and optimized interagency partnerships, coordination, and collaboration through its activities and continued to implement its government-wide strategic plan. In addition, the ICDR engaged with stakeholders and continued its ongoing activities to support its overall mission, goals, and objectives. These activities included

- restructuring the work of the ICDR to align with administration priorities;
- exploring the impact of COVID-19 on research institution finances, quality and efficiency, knowledge dissemination, preexisting disparities for researchers, research focus, and productivity;
- publishing a stakeholder engagement toolkit to provide staff and leadership of the Administration for Community Living (ACL) with guiding principles, promising practices, and resources to help enhance ACL's stakeholder engagement efforts;
- publishing a toolkit on medical rehabilitation with resources for people with disabilities and their caregivers, medical rehabilitation providers, medical rehabilitation researchers, and federal agencies focused on medical rehabilitation services and research;
- continuing the Government-Wide Inventory Working Group;
- relaunching and revisioning the Disability Data & Statistics Working Group;
- adding to the Government-Wide Inventory of Disability, Independent Living, and Rehabilitation Research – The Interagency Rehabilitation and Disability Research Portfolio;
- hosting a public stakeholder meeting;
- supporting continued collaboration among ICDR member agencies and partners by hosting regular executive committee meetings;
- continuing to enhance and expand the functionality of the ICDR website to ensure transparency and public access to news, research, funding opportunities, events, and resources in the field of disability, independent living, and rehabilitation research;
- continuing a Lunch and Learn webinar series highlighting strategies for addressing cultural and linguistic differences in disability research and providing information on the impact of the coronavirus disease of 2019 (COVID-19) pandemic on children and youth, post-COVID conditions, and implications for treatment.

### **GOVERNMENT-WIDE STRATEGIC PLAN ACTIVITIES**

In July 2014, WIOA mandated significant changes when it reauthorized the ICDR. As Public Law 113-128, WIOA included a new requirement for the ICDR to develop a comprehensive government-wide strategic plan for disability, independent living, and rehabilitation research.

The ICDR government-wide strategic plan was released by the U.S. Department of Health and Human Services in April 2019, and it serves as the guiding document for the executive committee and working groups. This section describes the strategic planning activities accomplished during FY 2022 under a select number of objectives. The full plan is available on the ICDR website.

# GOAL 1: IMPROVE INTERAGENCY COORDINATION AND COLLABORATION IN FOUR THEMATIC RESEARCH AREAS — TRANSITION, ECONOMICS OF DISABILITY, ACCESSIBILITY, AND DISPARITIES

### Objective 1: Identify current and planned agency research activities related to thematic framework areas

### The Impact of COVID-19 on Disability Research: A 2022 Update

COVID-19 has had vast local, nationwide, and global impacts across all fields of federal research. These new implications for federal research include impacts on research institution finances, quality and efficiency, knowledge dissemination, preexisting disparities for researchers, research focus, and productivity. An updated estimate of the impact of the pandemic on federal research from March 2020 through February 2021 calculated a financial loss of \$218 million and research output losses between 20 percent and 40 percent (Council on Government Relations, 2021). This paper provides an update to the first ICDR COVID-19 white paper and presents recent information on how the field of disability research has changed and adapted throughout the pandemic, highlighting important areas of new research, and discussing how the shift to virtual research methods has modified the research landscape. The paper is posted on the ICDR website at this link:

https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fpstrapiubntstorage.blob.c ore.windows.net%2Fstrapib%2Fassets%2Fimpact of covid 19 on disability research 2022 u pdate final 508 79739d83ee.docx&wdOrigin=BROWSELINK

### Medical Rehabilitation: Research and Resources for Interagency Collaboration in an Emerging Field

As the broad field of medical rehabilitation aims to address the complex needs of an aging population experiencing higher rates of chronic conditions, interagency collaboration is needed to innovate and drive the field forward toward this goal. Cost and the complex nature of interventions are significant challenges that often arise when conducting medical rehabilitation research. To promote increased interagency collaboration and address challenges in this field, the ICDR released a toolkit on medical rehabilitation. It is designed to provide resources for people with disabilities and their caregivers, medical rehabilitation providers, medical rehabilitation researchers, and federal agencies focused on medical rehabilitation services and research. The toolkit describes a wide range of current research and resources across federal agencies, examples of best practices and current interagency collaboration, and areas for future research and development in medical rehabilitation. The toolkit is posted on the ICDR website at this link:

https://pstrapiubntstorage.blob.core.windows.net/strapib/assets/ICDR Medical Rehab Toolki t 02 02 22 508 8555acb8c5.pdf

## GOAL 2: DEVELOP A GOVERNMENT-WIDE INVENTORY OF DISABILITY, INDEPENDENT LIVING, AND REHABILITATION RESEARCH

### The Interagency Rehabilitation and Disability Research Portfolio

During FY 2021, the ICDR Government-Wide Inventory Working Group had launched the Interagency Rehabilitation and Disability (IRAD) Research Portfolio (<a href="https://irad.nih.gov/">https://irad.nih.gov/</a>), a searchable database of government-funded research projects in the areas of disability, independent living, and rehabilitation research. In FY 2022, the ICDR added to the database to provide a publicly available resource that enables analysis of the federal research portfolio in disability, independent living, and rehabilitation research. The portfolio aids in collaboration and coordination of research activities across federal agencies and increases transparency and visibility for public and legislative stakeholders. To date, eight agencies have submitted data to the repository.

### **Lunch and Learn Series**

In FY 2022, the ICDR launched a *Lunch and Learn* webinar series on topics related to disability and rehabilitation research to highlight the work of partners and member agencies. Four sessions were held featuring the following presentation topics:

- Children and Youth with Disabilities in the Context of the COVID-19 Pandemic, presented by Dr. Emily Lund
- Understanding Post-COVID (Long COVID), presented by Dr. Elizabeth R. Unger
- The Pathogenesis of Long COVID and Its Implication for Treatment, presented by Dr. Steven G. Deeks
- Understanding and Responding to the Cultural and Linguistic Differences in the Conduct of Disability Research, presented by Tawara D. Goode

# GOAL 3: PROMOTE ONGOING STAKEHOLDER INPUT ON GAPS AND PRIORITIES FOR DISABILITY, INDEPENDENT LIVING, AND REHABILITATION RESEARCH

## Getting the Most Out of Stakeholder Engagement: A Toolkit to Better Understand and Measure Engagement

The toolkit is designed to provide ACL staff and leadership guiding principles, promising practices, and resources to help enhance ACL's stakeholder engagement efforts. It includes practical information about stakeholder engagement—how and when to do it and why it is important—as well as interviews and case studies with examples from across ACL. The toolkit also focuses on the importance of measuring and analyzing stakeholder feedback, an area often lacking in engagement planning. The toolkit is posted on the ICDR website at this link: <a href="https://pstrapiubntstorage.blob.core.windows.net/strapib/assets/ICDR">https://pstrapiubntstorage.blob.core.windows.net/strapib/assets/ICDR</a> ACL Stakeholder Toolkit 071922 508 a966ea809b.pdf

### **EXECUTIVE COMMITTEE MEETINGS**

The ICDR executive committee (EC) met throughout FY 2022 to develop action plans, implement strategic work plans, and discuss current and emerging research areas of interest to

the ICDR. The EC met virtually in January, February, and September of FY 2022. The meetings provided an opportunity for the EC members to convene and discuss strategic planning activities, continue work on their action plans, provide updates on current or upcoming activities, and share agency activities related to COVID-19.

Meeting summaries and any supplemental materials can be found on the EC page on the ICDR website.

### STAKEHOLDER MEETING

The ICDR held a stakeholder meeting in June 2022 for members, grantees, and other stakeholders. Discussion topics included

- an overview of the ICDR and agency activities focused on disability,
- impact of COVID-19 on people with disabilities,
- assessing disability questions used in national surveys, and
- disability equity.

A summary report from the stakeholder meeting can be found on the ICDR website.

#### **ENHANCEMENTS OF ICDR WEBSITE**

During FY 2022, the ICDR continued to populate the ICDR website (<u>ICDR.acl.gov</u>) with scheduled events, disability research news, and federally funded research products.

### **UPCOMING ACTIVITIES IN FY 2023**

To align ICDR's mission and vision in the most efficient manner with the goals of the current administration, focused work will be done across the following four focus areas: interagency disability data and statistics, equity, COVID-19 related activities, and Government-Wide Inventory. All new activities for FY 2023 and initiatives are being planned and executed around these focus areas and will inform the next iteration of its strategic plan.

The ICDR looks forward to ongoing collaboration and information sharing among federal departments and agencies as well as with stakeholders and grantees. These focus areas are crosscutting by design to allow for input and expertise from ICDR members and to allow federal agencies and the broader disability research community to contribute their strengths. Structurally, the existing subcommittees will not be disbanded, as it is possible that subcommittees will have ad hoc issues to address, but the topical areas of focus can be revisited as part of the annual planning process, based on the needs of the disability community and the priorities of the Administration.

The first focus area is on interagency disability data and statistics. This will involve moving forward with the Disability Data and Statistics Working Group, which focuses on establishing

greater coordination and collaboration related to disability statistics, terminology, and data collection. The working group will also host a State of the Science meeting in February 2023.

The second focus area is equity, reflecting the current Administration's focus on this topic. The EC will incorporate this priority as it develops a work plan for its activities over the coming year. The ICDR will continue to focus on COVID-19 and its impacts.

The focus area of COVID-19 is not meant to duplicate existing federal work or work groups but rather to allow for greater coordination and collaboration in terms of what is happening related to COVID and disability data and research, including Long COVID. Proposed activities for this topic include acting as a clearinghouse to connect people with federal resources on COVID-19 and disability research and a Lunch and Learn session or State of the Science meeting on the topic.

The focus area of the Government-Wide Inventory is designed to continue populating and sharing this tool. In addition to continuing to obtain data to be housed within the inventory, suggested activities include a promotional event of the Government-Wide Inventory and COVID-19-focused analyses and report based on available cross-government disability data.

Progress in these areas will assist other agencies and federal partners who are less familiar with data collection concerning disability and will strengthen the individual research efforts of the ICDR member agencies.

### **APPENDIX A: FEDERAL PARTICIPATION**

In addition to the statutory members, other federal and nonfederal partners contribute to the deliberations, events, and products of the ICDR. Some federal partners play key leadership roles on the ICDR by co-funding activities and providing resources to support achievement of ICDR goals.

### **Federal Government Agencies**

Executive Office of the President

U.S. Department of Education

Office of Special Education and Rehabilitative Services
Rehabilitation Services Administration

U.S. Department of Health and Human Services

Administration for Community Living

National Institute on Disability, Independent Living, and Rehabilitation Research

Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities

Indian Health Service

National Institutes of Health

National Center for Medical Rehabilitation Research

National Institute of Child Health and Human Development

National Institute of Mental Health

Office of Autism Research Coordination

National Institute of Neurological Disorders and Stroke

**Division of Neuroscience** 

U.S. Department of Labor

Office of Disability Employment Policy

U.S. Department of Transportation

Federal Highway Administration

Office of Operations Research and Development

U.S. Department of Veterans Affairs

Rehabilitation Research and Development Services

### **Independent Agencies and Government Corporations**

**National Science Foundation** 

Social Security Administration

### **Point of Contact**

For further information regarding this report, or to report any errors or omissions, please contact:

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